

CHOICE /LESS



REGINA: IS IT A LIFE?

Regina: When was the first time I felt like a mother? Oh my. In some ways I think I almost felt like a mother as soon as I was pregnant because it was the beginning of the possibility.

Jenn: This is CHOICE/LESS, a storytelling podcast from Rewire Radio about reproductive injustice and the laws that put people in choice-less situations.

I'm Jenn Stanley, senior staff reporter at Rewire, formerly RH Reality Check, and the host of this podcast.

Today we hear from Regina Vidaver, who, with her husband, mad the difficult decision in 200 to terminate her pregnancy at 29 weeks.

Regina's case is rare. Only about 1.3 percent of abortions performed in the United States occur after 29 weeks.

Most physicians generally agree that 24 weeks is about he point at which a fetus could live outside the womb. The Supreme Court case *Planned Parenthood v. Casey* determined that states could not ban abortion, or create an undue burden for a person seeking an abortion before the point of viability. But viability is tricky. It can vary from case to case, and medical advancements will continue to change the point at which a fetus could survive. Some state lawmakers have even tried to argue that viability occurs at conception because in vitro fertilized embryos can survive for three days outside the womb.

To make things more complicated, in 2003, then President George W. Bush signed into law a ban on a type of abortion procedure called intact dilation and extraction. This opened the door for states to start passing pre-viability bans such as the 20-week ban, which is in effect in more than a dozen states, with many more introduced every year. It is based on the unscientific claim that fetuses can feel pain at 20-weeks gestation.

I first heard Regina's story when she was speaking out against Wisconsin's 20-week ban. At the time when Regina had her abortion, she lived in Maryland, but she and her family currently live in Wisconsin, where, due to the state's many abortion restrictions, she almost certainly would not have been able to have her procedure.

Here's Regina's story.

Regina: I was first pregnant in 2000. We were trying. So my husband and I had been married for three years, and we had we got married while we were in graduate school, and so we had

moved, and we were in our first jobs, like we were staying there for a while, and we were financially secure. We were very, very ready to start a family. I was thrilled beyond belief to be pregnant and very, very much wanted this child.

The first time that we were worried that there was an issue with the fetus was at 15 weeks. We had a blood test, and the blood test was a screening test so not a diagnostic. It wouldn't tell us something was wrong but it was designed to screen and see risk for things, and it came back with a higher than average risk for Down Syndrome. And then we continued to do more tests to rule out Down Syndrome as a problem.

Jenn: Regina and her husband had decided early on that if the tests were positive for Down Syndrome, they would terminate the pregnancy.

Regina: I realize that different people will make different choices in a situation like that. But that was my perspective. I can remember telling my OB that if it were downs that I would terminate.

It was interesting in going through the process with him because he did tell us that if we did decide to terminate that he would not do that. That we would have to have another doctor to do the termination. And I fully understood that as a doctor who brings babies into the world, I can understand that he wouldn't want to terminate pregnancies but it was good for him to tell us that because it also helped us to know what to expect that if that were a direction that we were going to go that we would need additional consultation.

My views on abortion had always been very much that it is the person who is carrying the pregnancy who has the right to decide their life. That had always been my view, my husband shared that view, and we were very much aligned in our perspective that if there was something substantially challenging with the child that that wasn't a child that we wanted to bring into the world.

After the first blood test we did a second blood test, which now one week later actually showed an even higher likelihood that it was Downs, and so we made the decision to go through amniocenteses. To go through amniocenteses I had read quite a bit of literature about the risk of miscarriage because it is an invasive procedure, and at that point the risk of miscarriage was lower than the risk of us having a child with Down Syndrome.

Going into an amniocenteses is incredibly anxiety producing. It's, you know that you're going into something that in a wanted pregnancy that has the potential to end it. So you know certainly I was tense and it was challenging but it was very helpful to have the ultrasound technician telling me I see no signs of Downs here, and he, and to have him tell me he had seen many fetuses with Downs, and that he couldn't see any signs of it, and so that was reassuring during the process.

I don't know what it's like now because it's been a good long time now and things have progressed a bit, but at the time anyway it took two weeks to get results from amniocenteses. And so those two weeks were very tense. I can remember that I refused to buy maternity clothes even though that I was getting to the point that I needed them because I didn't know if I was going to be continuing this pregnancy or not. I can remember my birthday passed, and going out to dinner with my mother and my husband, and it was, I was not, it was not a happy birthday. Um, I

was very, very anxious and didn't know what the future was going to hold. And it was very difficult to be celebrating my own life at that moment when I didn't know what was going to happen with the fetus that I was carrying.

My husband was always supportive, always by my side, always asking me how I was. It is very, very different for the husband than it is for the woman though because as the one carrying the fetus you're the one that can feel it moving inside of you. He cannot. He cannot know what it's like to be living all the time knowing that this might not work out.

When we got the results back from the amniocentesis we were thrilled because it showed that everything was normal, and we started sort of breathing again. I remember being very, very happy, immediately went out and bought maternity clothes, was starting to think about the future, we started talking about names. You know, we were very, very much thinking about his due date and how it would be. And it was it was the best time for three weeks or four weeks or something like that. It was very, very happy

So we had actually found out the sex of the baby even before the amniocenteses. I had had some other medical issues that had caused me to have an ultrasound even earlier, and it was very clear that it was a boy. So we actually knew the sex of the baby at about 14 weeks.

After the amnio we went forward again, we were planning everything, we had our regular visits with the OB, and as part of the normal progression of a pregnancy the normal practice was to have a diagnostic ultrasound at 20 weeks at the midpoint of the pregnancy. And I felt that, well we'd gone through all of this and we've seen it so many times, and we had the positive amnio result everything was fine, let's wait until 21 weeks.

So we went in at 21 weeks and I was literally I would say giddy with excitement. I mean it was just fantastic. Um to be able to see him, and see his little hands, and his little face, and see him moving around. And it was really incredible because the ultrasound technician did not say a word about any problems. She just said at the end, 'You know just a moment the radiologist will be in to talk to you.'

The way that it was so the the ultrasound technologist when the ultrasound tech left the room my husband and I were just we were literally reminiscing about what we had just seen. We were like, 'Oh did you just see his little hands, and his little feet, oh he's so cute.'

And then the two radiologists walked into the room and really gave us no, there was no segue, it was just, 'Hi there's something going on, and we want to take a closer look.' And immediately launched into 'There's a growth on his back. We don't know where it's coming from. It might be coming from his kidneys. That would be really bad. This really could be nothing, or this could be really terrible.'

And it was as though we had just been hit by a bomb. I mean we had gone from giddy, and happy, and delighted, and hopeful for the future, to crestfallen in moments.

The process of getting the MRI: it's kind of flooding back right now. So first of all it was very, very emotional because we had just had the ultrasound where we had essentially learned that the tumor had advanced quite substantially in the last few weeks. And so this was really the

point where it went from, this could be bad, to this is really bad. And so this was really the point at which it was kind of all coming home that this might not work, that we might not be able to have this child.

And so we were in a room by ourselves, and I had to sign paperwork because it is not a standard practice to do an MRI on pregnant women. And so we had to sign something saying that this was experimental, and basically that we would hold the hospital harmless for anything that happened as a result of it.

Um and then for anyone who's ever had an MRI, it's very loud to go into those machines, and they give you earphones, but I had a little guy inside me flipping around, and you know he didn't have little headphones on to keep his ears from hearing the really loud booms or clicks. So he was very, very active during the procedure and um that made it harder. It made it harder because I had to be in there longer, and it made it harder because you know I could feel him. I could feel him moving and knowing that this wasn't necessarily going to come out for the better.

The radiologists met with us after the MRI to go through the images, and she showed us some of the clearer pictures. He was moving very much so it was not the easiest to get the good images. But if you can imagine what it's like to grasp a cup handle, the tumor was as though it was you had grasped but not quite closed your fingers. So the tumor was wrapped around his spine, and it was not crushing it yet but that certainly was the direction that it looked like it was going.

And I do remember the radiologist talking to us about our options, and she said, 'You guys are young, you're gonna have more chances. You might think about ending this.'

And um again I think that helped us know that what we were already thinking about what we were already talking about was more acceptable.

Jenn: So Regina and her husband decided to speak to their Rabi about the spiritual ramifications of terminating this pregnancy.

Regina: And he I remember him, when we kind of laid the news onto him, he kind of just, kind of wiped his brow with his hand and was kind of incredulous and certainly was empathetic with us. And then we talked through some of, sort of the, the religious aspects of pregnancy termination and what it would mean and he was incredibly supportive of us the entire time.

From our Rabi's point of view, within Judaism, it is always the woman's life that comes first. So if there were a situation in which the woman's life is potentially impacted by the fetus, such that the woman could die for example, it was imperative that you remove the fetus because the fetus is potential life and the woman's life is what you have to protect.

We had the benefit of having a Rabi who had been a bioengineer, so he did have quite a bit of biology background and really understood sort of the medical ramifications of what we were facing and the things that we were deciding. So it was maybe easier than if we had had a Rabi without that kind of background. The religious teachings were that if this is something that could not yield a life that it was not a taking of a life so to speak.

Jenn: But it would still be a few weeks before the biopsy results came back. Until then, Regina and her husband held onto the possibility that maybe everything would be ok.

Regina: The biopsy came back as a spindle cell carcinoma, and it termed an infantile fibrosarcoma. My husband and I both have backgrounds in biology so we read the primary literature to find out everything we could about this. Our doctors had never seen anything like this before it was a very rare cancer, and it had never been detected before in utero so we were all learning at the same time. And what we found was that it had a 30 percent chance of metastasis. When it occurred on a limb the preferred treatment was amputation. And that in every case where it had appeared on a trunk of a child under 2 they had all died.

So we were facing the possibility of giving birth to a child who would need surgery and chemotherapy and would likely die anyway. So we decided that that would be cruel to a baby to put it through that. And especially, a baby doesn't know why you're hurting it. You know, with a, even a relatively young child he can understand if there's a cancer and you need to get rid of it and that will make it better but a baby can't know that. So we felt that it would be wrong to bring a child into the world under those circumstances and we made the very difficult decision to end the pregnancy.

The period of time when I was walking around very visibly pregnant during the time when we were going through all of this it was the hardest time in my entire life. I can only describe it as mental torture. I had removed myself from everything except the cocoon of my husband and going to work and that was it.

And the way it feels to walk around having your baby dying inside of you, and people not knowing that on the outside and being like, just going to CVS, 'Oh is this your first? Oh how far along are you? Oh you must be so happy.' It was a living hell.

Once we made our decision to move forward with the termination I was past 24 weeks, so the doctor said the hospital ethics board would have to approve this because I would have the termination procedure at the hospital.

Having other people meet to talk about our decision was, um, the best way that I could describe it was, it felt really rude and intrusive. At the same time we understood. And I will say that it also felt um reinforcing of our decision for them to come back with a positive decision that they said 'Yes, you can go forward with this.'

So when the day came we went to the hospital in the morning, and we you know parked the car, went up to the maternal fetal medicine suite, checked in, and probably a nurse somebody let us into the room and I sat down on the table and I just broke down crying. I just, the best thing to say is I just lost it. And the doctors and nurses all kindly left the room and just let my husband and me be. Until I could calm down enough to lie down on the table, and they kind of they were hovering outside the door.

When the staff walked back in the room I think they just wanted to check that you know I was ready to go forward, and, um, could be calm enough to do the next step. Then we asked the doctor we said we didn't want to see the monitor on, and he said no of course not. And we asked him we do want to know if there's been a change. If there's been a miracle that's occurred if the tumor suddenly started to regress, started to shrink, we want to know that. And he had the ultrasound wand on my belly for a little bit he was pausing quiet for a bit, and he said,

'There has been a change.' And I think he always used the term youngster. He was very specific in his terminology. And he said, 'The youngster is in heart failure.' And my husband and I literally went (deep breath) because now we knew that we had no control. Yes we were ending things a little earlier than they would have otherwise, but they would have ended no matter what. He kind of said here's what's gonna happen. I'm gonna inject the potassium chloride in his heart. You're not going to feel much of anything. It's a very small needle. And really what I felt was that my belly was quiet. So um, afterwards, it was a strange piece in my body.

After the potassium chloride was injected and he was still then we went down and saw a nurse and we had to go to a different floor of the hospital, and she said they were going to insert laminaria into my cervix, and they were made out of seaweed and they were all different diameters. It was painful but it was like it was pain and it was pressure. It's just it's an area that's not supposed to have stuff shoved into it. It's just really, really, really uncomfortable. Way worse than giving birth naturally.

And then we we got lunch we went to subway in the hospital and got something to eat. And then we went home and watched movies just to try to keep our minds off things.

Jenn: The next day she went back to the hospital for the still birth.

Regina: They had prepared me that my milk would come in, and that that would be painful, especially because I wouldn't have anybody to nurse.

I slept overnight at the hospital, and I was released the next day. And we went home, and, um one thing that was difficult was that I talked a little bit about working with our Rabi, And so we had we had prearranged a burial plot, which the funeral home had actually not charged us for. It was really wonderful of them. And my mother in law convinced me that if this was not a life and therefore we could do the termination, that we shouldn't go to the funeral. There shouldn't really be a funeral. So our Rabi buried our little guy. And that is the one piece that I regret, because I think that I would have had a little bit easier time grieving and closure if I had been able to see him buried.

And I can remember the first mother's day after the loss was horrible, it was very, very hard for me. And I told my husband, 'I need you to wish you happy Mother's Day.'

And he kind of was like, 'I don't know why you would want me to do that,' and I was like, 'No I need you to do that.'

Jenn: Eight months later, Regina found out she was pregnant again. Regina and her husband now have two children, a daughter and a son. They live in Wisconsin, where the state's restrictive abortion laws would have made her situation much more difficult.

One of the reasons that I actually spoke out against the 20-week abortion ban is I felt like I needed to do it for my own children. To show them that bravery in the face of certain defeat is the most brave you can be. Um. That's the model that I want to be for my children.

Jenn: This episode of CHOICE/LESS was produced by me, Jenn Stanley, for Rewire Radio. With editorial oversight by Mark Faletti, our director of multimedia. Jodi Jacobson is our editor-in-chief. Brady Swenson is our director of technology.

Music in this episode is by Doug Helsel and Robert Andersson, producer of the Awful Grace podcast.

Special thanks to all the staff at Rewire.

For more information on regina's story, and for comprehensive news, commentary, and analysis on other reproductive and sexual health and justice issues, you can check out our website at Rewire.news.

Thanks for listening.